Comparative Analysis of Evidence-Based Transition Practices in a Pediatric Spina Bifida Clinic

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Dedication

My interest in transition started my patient Phillip and his mother. When discussing Phillip's future with his mother, she said the following profound statement with tears in her eyes, "Who will take care of my son when he gets too old to come to the Myelo Clinic?" This project is dedicated to Phillip, his mother and every patient and family I am privileged to serve in the Myelomeningocele Clinic at Nationwide Children's Hospital.

Abstract

Problem: Medical advances in the treatment of spina bifida (SB) have resulted in life-long need for healthcare. A pediatric medical center (PMC) in an urban Midwest setting provided care to adult patients within a pediatric clinic construct.

Purpose: This DNP capstone project: a) compared and contrasted evidence-based best practices with current practices in the PMC SB Clinic to determine gaps, b) developed a best practices transition protocol and c) proposed future directions for improvement of transition care.

Findings/Results: Critical appraisal of transition literature revealed three major themes: a) position statements, b) patient/family perspectives and c) foundations of transition programs. A best practices transition protocol was created based on these themes. Evidence-based best practices compared to PMC SB Clinic practices revealed the following major gaps: a) no available multidisciplinary adult SB Clinic, b) no formal transition plan, c) no use of life course model foundation, d) no Transition Coordinator and e) no cumulative health summary. Proposed future directions for adult transition care included introduction and implementation of evidence-based best practices and creation of a new program for adult SB care in an adult center or within the PMC SB Clinic.

Conclusions/Implications: Comparison of current practices in a PMC SB Clinic compared to evidence-based best practices revealed gaps in clinic practices for adult SB care. This DNP Capstone Project has the potential to serve as a benchmark for improvement of current SB transition care and future development of a formal transition program in the PMC SB Clinic.

Comparative Analysis of Evidence-Based Transition Practices in a Pediatric Spina Bifida Clinic

Chapter One: Introduction

Introduction to the project

Spina Bifida (SB), a congenital anomaly that results in the failure of fusion of the caudal neural tube, is one of the most commonly occurring birth defects of the central nervous system occurring in 0.17 to 6.39 per 1,000 live births or approximately 1500 infants born each year in the United States (Bowman, Boshnjaku, & McLone, 2009; Le & Mukherjee, 2015; Mitchell et al., 2004). The term SB encompasses a broad range of malformations of the central nervous system that in its most severe form, myelomeningocele, can result in life long disabilities that can include paraplegia, hydrocephalus, bowel and bladder dysfunction, orthopedic dysfunction, intellectual and developmental disability (Bowman, Boshnjaku, & McLone, 2009; Greenberg, 2010; Mitchell et al., 2004). Due to medical and surgical advances, 85% of children born with SB can be expected to reach their early adult years and will require a life-long commitment to their health by the health care community (Bowman, McLone, Grant, Tomita, & Ito, 2001).

In 2002, the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine acknowledged in a consensus statement that youth with special health care needs (YSHCN) experience difficulties in the process of transition to adult health care (American Academy of Pediatrics [AAP], 2002, p. 1304). As a directive of this consensus statement, a mandate was proposed that by age 14 a transition plan to adult health care should be in place for YSHCN (AAP, 2002). Healthy People 2020 also acknowledged the importance of transition planning declaring an objective that providers of care for YSHCNs discuss transition planning as a fundamental part of their care (U.S. Department of Health and Human Services [DHHS], n.d.).

The lack of transition planning represents a national and worldwide challenge. The National Survey of Children with Special Health Care Needs found that only 14% of young adults met Maternal Child Health performance measures for successful transition (Lotstein, McPherson, Strickland, & Newacheck, 2005). Inadequate transition to adult health care for YSHCN's has life-long implications. Studies have demonstrated that during the process of transition YSHCN's experience deterioration in their health care status that can result in life-long implications (Campbell, O'Neill, While, & McDonagh, 2012; Dicianno et al., 2008).

This Doctor of Nursing Practice (DNP) capstone project explored current transition practices in a SB Clinic that was housed within a major pediatric medical center (PMC) in an urban Midwest setting. The PMC offered a multidisciplinary SB Clinic staffed by pediatric board certified APRN's, physicians and other pediatric providers that served over 400 patients with SB. Of these 400 patients, approximately 20% of the patients were over the age of 21. Despite this patient/provider construct, the SB Clinic did not have a formal transition program to adult health care in place. This resulted in the adult SB patient receiving care in a pediatric model that was not focused on the changing health care needs of the adult patient. Additionally, as new patients were brought into the SB Clinic, numbers continued to grow with finite pediatric resources. The lack of a formal transition program for the patient with SB to adult health care represented a significant problem to patients, families, the health care system and its resources. Therefore, the delivery of care and the long term health of SB patients at the PMC SB clinic had the potential to be improved through implementation of evidence-based best practices for transition to adult health care.

Purpose

The SB Clinic at the PMC provided comprehensive interdisciplinary care to patients ranging in age from birth into the fifth decade of life. Institutional prevalence data from the PMC SB Clinic revealed that approximately 20 percent of patients attending the PMC SB Clinic were over age 21. Although this population faced many challenges, the lack of a formal program for transition to adult health care represented an area in need of improvement. The purpose of this project was to develop an evidence-based best practices protocol for transition to adult health care for the young adult with spina bifida (YASB).

Significance to Nursing, Health Care and the DNP Essentials

In a 25 year landmark study of SB, Bowman et al. (2001, p. 119) set the course for transition stating that "One of the greatest challenges in medicine today is establishing a network of care for adult patients with SB". Longitudinal research on patients with SB has demonstrated that 85% survive into adulthood, 73% maintain motor function, and 85% attend or graduate from high school or college (Bowman et al., 2001; Dillon, Davis, Duguay, Seidel, & Shurtleff, 2000). These factors set the stage for the patient with SB needing a life-long commitment to their well-being by the health care community.

Essentials

In 2006, the American Association of Colleges of Nursing established eight core competencies that serve as the foundation for DNP educational preparation. This DNP capstone project reflected several of these competencies.

Essential I: Scientific Underpinnings for Practice (American Association of Colleges of Nursing [AACN], 2006). A focus group provided a method to obtain comprehensive knowledge regarding the attitudes, perceptions, beliefs and experiences of the providers in the SB clinic with

transition (Doody, Slevin, & Taggart, 2013; McLafferty, 2004; Then, Rankin, & Ali, 2014). Because little was known about how transition care was provided in the SB clinic, a focus group investigated knowledge regarding the topic of transition and provided a better understanding of the phenomena at the PMC (Doody, Slevin, & Taggart, 2013). The transition protocol was founded on evidence-based, critically appraised literature that was put through a rigorous review process.

Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking (AACN, 2006). The DNP student served in a leadership role on the subject of transition during the execution of the focus group. The transition protocol served as an evidence-based foundation that has the potential to guide the future development of a formal transition program for the PMC that serves the young adult with SB; a quality improvement initiative.

Essential III: Clinical Scholarship and Analytical Methods for Evidence-Based Practice (AACN, 2006). The focus group was conducted through the presentation of semi-structured questions during a one hour digitally recorded session. Following the focus group, the recording was transcribed, data was coded and key themes were identified regarding the providers' experiences and beliefs surrounding transition (Beyea & Nicoll, 2000; Freeman, 2006). The evidence-based best practices protocol was created through a rigorous analytical process based on clearly identified foundational methods. In the future, the PMC has the option to use the data obtained from the focus group and the evidence from the transition protocol to guide the development of a formal transition program.

Essential V: Health Care Policy for Advocacy (AACN, 2006). During the process of the DNP project, policy and current health care reform issues were explored that impacted the patient with SB and the process of transition to adult health care.

Essential VI: Interprofessional Collaboration for Improving Patient and Population Health Outcomes (AACN, 2006). The focus group represented an interdisciplinary team that explored the concept of transition. Inter-professional factors that influence transition to adult health care for YSHCN's were explored in the transition protocol.

Essential VII: Clinical Prevention and Population Health for Improving the Nation's Health (AACN, 2006). The focus group explored transition experiences with the SB Clinic team whose goal is to prevent long term complications associated with the significant co-morbidities of SB. The focus group was a first step to explore transition with a future goal to develop an evidence-based transition program to improve health for the young adult with SB. The objective of the transition protocol was to provide an evidence-based best practices guideline that has the potential to serve as a foundation for the development of a formal transition program. An evidence-based transition program has the potential to promote health and prevent illness for the young adult with SB.

Essential VIII: Advanced Nursing Practice (AACN, 2006). During the focus group, the DNP student served in an APRN leadership role through exploring the experiences of a multidisciplinary team to determine themes of current transition knowledge and practices. Development of the transition protocol was based on a comprehensive and systematic assessment of SB and YSHCN literature surrounding transition to adult health care. In its final form, the protocol demonstrated advanced clinical judgment, ability to evaluate systems and ability to critically evaluate evidence to design a best practices protocol to improve patient outcomes (AACN, 2006).

Project Objectives

- Compare and contrast evidence-based best practices with current practices in a PMC SB Clinic to determine gaps in transition to adult care for the YASB
- Development of a transition to adult health care for YSHCN best practices protocol
- Propose future directions for improvement of transition care in the PMC SB Clinic

In summary, the purpose of this DNP capstone project was to provide increased knowledge regarding the phenomena of transition care in the PMC SB Clinic, to synthesize current and evidence based best practices and to provide a framework for the conceptualization of formal transition programs.

Chapter Two: Review of Literature

Theoretical Framework

The creation of an evidence-based protocol of best practices for transition to adult health care was guided by two theoretical frameworks. First, the life experience of the patient with SB was comprehensively supported by the construct of the Glass-McAtee Model (Glass & McAtee, 2006). The Model for Evidence-Based Practice Change provided an evidence-based method to create a best practices transition protocol to guide practice change (Ciliska et al., 2011; Rosswurm & Larrabee, 1999).

Glass-McAtee Model

The conceptual framework created by Thomas A. Glass and Matthew J. McAtee (see Appendix A) proposed a multilevel behavioral-social-ecologic paradigm that integrated the axes of time and hierarchy of systems in a flowing construct to explore behavior and health (Glass & McAtee, 2006). The underpinning of this DNP capstone project was based on the construct that the life experiences of the YASB was impacted by multiple interwoven factors including: (a) predisposing Micro/Biologic factors, (b) Mezzo/Risk Regulators for Health Behavior, and (c) Macro/Environmental/Global factors.

At the *Micro-level* many YASB depend upon the support of their parents for basic daily care and mobility. Many YASB, because of bowel and bladder incontinence, constantly face the concern of accidents and odor while in the social environment with peers and friends. This can result in isolation not only from peers but can result in overall social isolation (Betz et al., 2010).

At the *mezzo-level* deficits in executive cognitive functioning and overall developmental delay impact many YASB and therefore affect their experiences at school and within the community at large (Greenberg, 2010). Because of the severe impact that SB has upon mobility,

YASB are challenged with navigating the schools and communities in which they live. Impaired mobility results in decreased ability to perform active physical activities which can impact overall health. As YASB transition into adulthood, their ability to obtain self-sustaining employment presents many challenges which can have a profound effect upon their integration into society on multiple levels (Ridosh, Braun, Roux, Bellin, & Sawin, 2011).

Macro-level forces such as programs that impact health on a state and federal level such as health insurance programs and programs for the chronically ill represent a continual and ever changing concern that impacts the YASB. Because SB results in life long health care needs, the macro-level impact is one that has significant influence on the health and future of the YASB (Callahan & Cooper, 2006).

Global-level influences such as changes in the political climate for the support of the chronic needs of the YASB, occurrences of economic downturns or recessions or overall changes in the economy can impact the present and future health of the YASB. Both domestic and foreign advancements in health technology for the YASB could result in improvements in quality of life.

Model of Evidence-Based Practice for Transition Protocol Project Implementation

Development of an evidence-based protocol of best practices for transition to adult health care has the potential to influence a practice change for the PMC SB clinic in the future. The Model for Evidence-Based Practice Change (MEBPC) by Rosswurm and Larrabee (1999), revised in 2009, guides practice change through principles of "assessing need for practice change, locating and critically analyzing the best evidence and designing, implementing, evaluating, integrating and maintaining practice change" (Ciliska et al., 2011, p. 255).

The development of the evidence-based protocol for transition to adult health care was facilitated by the six step process of the MEBPC (Rosswurm & Larrabee, 1999) (see Appendix C). Step one: assess need. The need for a transition plan has long been recognized by the evidence, patients, parents, professional organizations and members of the PMC SB clinic team. Additionally, the mission statement of the PMC declared an objective to "better manage populations with historically poor outcomes and high costs" (NCH, n.d., p. 1). Initial protocol development and literature review was based on the PICO question and institutional prevalence data of YASB that attended the SB clinic.

Steps two through four: Locate and critically analyze the evidence and design practice change. These steps were performed as a part of protocol development through rigorous standards. Step two was facilitated through the underpinnings and influence of the Glass McAtee Model (Glass & McAtee, 2006). Search terms developed from the PICO question guided the literature review. Multiple databases used search terms to gather evidence using meaningful limits. Step 3, evidence included in the protocol was based on the PRISMA method (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) and critically evaluated by Rapid Critical Appraisal Tools and Evaluation/ Synthesis Tables (Melnyk & Fineout-Overholt, 2011). Step 4, development of the transition protocol, was guided by the Appraisal of Guidelines for Research and Evaluation II Instrument which was applied to the critically appraised evidence (Brouwers et al., 2010).

Steps five and six, implement, evaluate, integrate and maintain change, are projected to occur if the PMC adopts the evidence-based best practices found in the transition protocol following the completion of the DNP capstone project.

Review of Literature

In this DNP capstone project an exhaustive and critical review of the literature sought to create an evidence-based protocol of best practices regarding transition to adult health care for the YASB (see Appendix E). An exhaustive review of the literature discovered what is known, what is not known and what needs to be discovered regarding best practices for transition to adult health care. A critical analysis of the literature assessed the quality of the findings and determined their clinical significance. Best practices discovered have the potential to guide future development of a formal transition program at the PMC if the proposed transition practices align with the mission and values of the organization.

PICO Question

The DNP project was based on the following PICO question that guided the literature review: Among young adults with spina bifida (P) could an evidence-based transition program from pediatric to adult health care (I) compared to the current care provided at the PMC that lacks a formal transition program (C) affect prevention and management of chronic conditions (O), management of changing needs (O) and patient/family satisfaction (O)?

Search Terms, Vocabularies and Databases Queried

Search terms that were developed from this PICO question included: (a) young adult with spina bifida, (b) transition to adult care, (c) management of changing needs, (d) management of chronic conditions, (e) patient satisfaction, (f) family satisfaction, (g) spina bifida, (h) youth with special health care needs, (i) transition and, (j) adult care. Databases that were queried include: (a) PubMed, (b) Cochrane Library, (c) CINAHL, (d) National Guideline Clearing House, (e) Web of Science, (f) Health Source: Nursing/Academic Edition, and (g) Ovid MEDLINE. MeSH

terms identified in the PubMed database search included: (a) spinal dysraphism, (b) transition to adult care, and (c) young adult.

The Google Chrome search engine and The Ohio State University Health Sciences Library System were used to conduct a search through the identified databases using search terms determined from the PICO question. Within all databases, with the exception of the National Guideline Clearing House, a time limit of the past 10 years was placed on the search. In the PubMed database, systematic reviews were queried. In the CINAHL database, these limitations were queried: (a) research article, (b) synthesis, and (c) evidence-based practice.

The preferred reporting items for systematic reviews and meta-analyses (PRISMA) method (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) defines a systematic review of literature as a "review of a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant research" (Page et al., 2014, p. 1). The PRISMA method operationalizes a four-phase system of identification, screening, eligibility and inclusion of evidence to assist with the process of reporting literature in systematic reviews. Once literature was identified through search terms, it was placed through the systematic four phase PRISMA process to determine if it proceeded to the next phase of inclusion in the protocol, critical appraisal (see Appendix B).

Critical Appraisal of Transition Evidence

Evidence that was included in the protocol was reviewed utilizing the PRISMA search method to determine if the evidence was valid, reliable and applicable and was then critically appraised through methods described by Melynk and Fineout-Overholt (2011). Evidence gathered through an exhaustive literature review was primarily qualitative but also included case-control studies, cohort studies, practice guidelines and expert opinions. Critical appraisal of

evidence ensured relevance and applicability to the development of the best practices transition protocol (Melnyk & Fineout-Overholt, 2011). A protocol that is developed based on critical appraisal of evidence can be used to develop best practices leading to a positive impact on transition to adult health care for the YASB.

Critical appraisal of evidence facilitated the evaluation and subsequent determination of the highest quality of evidence that guided protocol development (Melnyk & Fineout-Overholt, 2011). The evidence that was discovered through the PRISMA method was put through the rigor of the appropriate rapid critical appraisal tool based upon the level of evidence that was discovered. Rapid critical appraisal tools that were included: (a) quality improvement project, (b) qualitative study, (c) mixed method study, (d) literature review, (e) expert opinion, (f) descriptive study, and (g) cohort study (Melnyk & Fineout-Overholt, 2011).

Evaluation and Synthesis of Evidence

Once the obtained evidence was critically evaluated it was studied further using Evaluation and Synthesis Tables (Melnyk & Fineout-Overholt, 2011). Evaluation Tables facilitated organization of evidence in the categories of: (a) conceptual framework, (b) design/method, (c) sample setting, (d) major variables studied, (e) outcome measure, (f) data analysis, (g) level of evidence, (h) findings, (i) quality of evidence, and (j) critical worth to practice. Synthesis Tables further facilitated protocol development through organizing the evidence into translatable categories specific to protocol development including: (a) key elements of transition programs, (b) patient preferences, (c) patient characteristics and (d) expert opinions.

Related Research and the DNP Essentials

Literature and research surrounding best practices for transition from pediatric to adult health care (TPAHC) for the YASB were organized as they related to the corresponding DNP Essential: scientific underpinnings, leadership, evidence-based practice, policy, inter-professional collaboration, and clinical and population health.

DNP Essential II: Transition and Organizational/Systems Leadership for Quality Improvement and DNP Essential VI: Interprofessional Collaboration for Improving Patient/ Population Health

TPAHC for the YASB has been found to be a national concern of the health care system. Studies involving youth YSHCN have demonstrated that only 14% met Maternal Child Health performance measures for successful transition (Lotstein et al., 2005). Less than 17% of YSHCNs receive appropriate guidance and support for transition to adult health care (McPherson et al., 2004; Scal & Ireland, 2005). YASB experience limited access to adult providers and specialists due to provider lack of experience with the disease and low reimbursement patterns (Young et al., 2006). Ineffective TPAHC has the potential to result in significant long term health effects and secondary impairments (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). Current models of transition have been found to be ineffective in their organization and deficient in their education of youth regarding the actual process of transition to adult health care (Doug et al., 2011; Young et al., 2009).

The physical and disease influence of SB results in significant impact on health care for the YASB. YASB are less likely to have sustained employment and health care costs of SB are three to six times greater than the general population (Dicianno et al., 2008; Liptak et al., 2010). Studies have shown that YSHCN fail to get medical care, have significantly greater unmet health

care needs and have limited constant sources of health care compared to the general population (Callahan & Cooper, 2006; Dicianno et al., 2008; Ruck & Dahan-Oliel, 2010). In many cases, the inability to obtain private health insurance results in limited health care options such as wheelchairs and other necessary durable medical equipment resources (Callahan & Cooper, 2006; Ruck & Dahan-Oliel, 2010).

The impact of SB results in disparity to access care. YASB are more likely to be covered by public assistance and, secondary to low reimbursement levels, are denied access to care (Berens & Peacock, 2015; Wang, Wiener, Ross, & Routh, 2015). Research has shown that YSHCN face significant barriers to adult health care including inability to afford care due to poverty, limited access to private insurance or the inability to obtain comprehensive medical insurance, and limited Medicaid and SSI coverage of needs such as durable medical equipment (Callahan & Cooper, 2006; Doug et al., 2011; Reiss, Gibson, & Walker, 2005). Minority YSHCNs are less likely than non-minority youth to have a formally developed transition plan in place (Scal & Ireland, 2005).

The adult health care system, as it currently exists, does not support an effective seamless transition to adult health care for the YASB. Adult systems have been found to be focused on needs of the elderly and not on the needs of YSHCN's (Reiss et al., 2005; van Staa, Jedeloo, Van Meeteren, & Latour, 2011). Limited experience and the inability of adult health care providers to manage the complex chronic needs of YSHCNs have been acknowledged as concerns of both pediatric and adult providers (Binks, Barden, Burke, & Young, 2007; Callahan & Cooper, 2006; Doug et al., 2011; Reiss et al., 2005; van Staa et al., 2011; Young et al., 2009). The time required and multifactorial responsibilities in managing the care of YSHCNs, have been documented as significant barriers to access adult providers (Scal, 2002). Most adult models of

care for persons with multifactorial conditions are specialist driven. The lack of a multidisciplinary construct results in decreased care coordination (Doug et al., 2011; Reiss et al., 2005; van Staa et al., 2011; Young et al., 2009). Because some patients with SB face cognitive challenges, pediatric models of care have been identified as better prepared to meet the special needs of the intellectually disabled (Reiss et al., 2005).

The pediatric health care system, as it exists today, does not facilitate a seamless TPAHC for the YASB. Child centered providers have acknowledged the inability to "let go" of patients that they have cared for during their entire lifetime (Binks et al., 2007; Doug et al., 2011). Adult models of care are patient centered instead of family centered, encourage self-responsibility and discuss adult health care needs and sexuality. When compared to pediatric models that are based on nurturing and family centered principles the transition to an adult model of care can result in parents and youth experiencing stress, anxiety and resistance to leaving pediatric providers (Binks et al., 2007; Doug et al., 2011; Nishikawa, Daaleman, & Nageswaran, 2011; Reiss et al., 2005; Scal, 2002; vanStaa et al., 2011). As young adults are transitioned to adult care providers, an incomplete transfer of a lifetime of records from the pediatric provider to the adult provider has the potential to result in compromised safe transfer of care (Binks et al., 2007; Doug et al., 2011; Reiss et al., 2005).

Despite the above findings, if a transition program is carefully planned it has the potential to provide a method to coordinate multiple health care service needs such as medical supplies and specialist services (Woodward, Swigonski, & Ciccarelli, 2012). If the process of transition is not addressed proactively, it will result in further stress to an already inefficient health care system that cannot be sustained.

DNP Essential V: Health Care Policy for Advocacy in Health Care

In 2002, the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine, acknowledged in a consensus statement that YSHCN experience difficulties in the process of transition to adult health care and proposed that "by age 14 a health care transition plan to adult health care" should be in place (AAP, 2002, p. 1305). Healthy People 2020 acknowledged the importance of transition planning proposing that providers discuss transition planning as a fundamental part of their care (DHHS, n.d.). In 2011, the AAP went a step further recommending that YSHCN have in place portable/accessible medical summaries, action-oriented plans to track current problems/health needs and care coordination during transition to adult health care (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authorizing Group, 2011).

Changes in the legal rights of the disabled through rulings such as the 1975 Individuals with Disability Education Act and the 1990 Americans with Disability Act served to change expectations for the disabled and set the stage for increased integration into the health care system construct (Americans with Disabilities Act of 1990, 1990; Rehabilitation Act of 1973, 1973; Mukherjee, 2007). The Patient Protection and Affordable Care Act of 2010 provided hope for insurance coverage for YSHCN through the extension and mandate of certain benefits. However, it is not clear how the interpretation of this Act will impact those undergoing the process of transition (Patient Protection and Affordable Care Act, 2010; Sharma, O Hare, Antonelli, & Sawicki, 2014). Affordable Care Organizations, the Center for Medicare and Medicaid Services (CMS) incentive program and the Meaningful Use of Electronic Health Record Incentive Program show promise for developing financial incentives to support transition

(Sharma et al., 2014). It is clear that policy issues have a significant impact on transition for YSHCN.

DNP Essential VII: Clinical Prevention and Population Health

More YSHCN are surviving into adulthood and likely will develop chronic diseases that will require life-long management (Sawyer, Drew, Yeo, & Britto, 2007). Studies have found that YSHCN have little guidance in TPAHC and experience barriers to access to adult care (McPherson et al., 2004). The process of ineffective TPAHC has the potential to result in significant long term impact on young adults with SB. The Cochrane Collaboration (Campbell, O'Neill, While, & McDonagh, 2012) has identified that the process of TPAHC can result in deterioration in the health of YSHCN. Studies have found that young adults with SB have the lowest overall health scores compared to other YSHCN, fail/delay seeking care, cannot name a PCP, and ineffective transition has resulted in adverse health outcomes (Callahan & Cooper, 2006; Crowley, Wolfe, Lock, & McKee, 2011; Dicianno et al., 2008).

Routine prevention of common conditions such as high cholesterol and blood pressure is imperative to prevent comorbidities and hospital admissions (Dicianno et al., 2008; Liptak, Garver, & Dosa, 2013). Multiple studies have demonstrated that the YASB is more at risk for comorbidities due to low activity levels, declining autonomy and self-care abilities and risk of functional deterioration (Dicianno et al., 2008; Liptak, Kennedy, & Dosa, 2010; Roebroeck et al., 2009).

Effective transition to adult health care has the potential to delay or even prevent chronic health conditions associated with SB. TPAHC is the time in the life of YSHCN when health behaviors such as obesity and inactivity are established, influencing the health care system of tomorrow (Campbell, O'Neill, While, & McDonagh, 2012; Sawyer, Drew, Yeo, & Britto, 2007).

Studies have proposed that effective TPAHC can serve to develop independence, build inner strength (Ridosh, Braun, Roux, Bellin, & Sawin, 2011), involve the YSHCN in self-decision making (Blum et al., 1993; Cox et al., 2011) and give YSHCN a voice in what they wish to receive from their medical care (Sawyer & Macnee, 2010).

Literature supported the need for a formal transition plan to adult health care for the YASB. Through a focus group, this DNP capstone project sought to evaluate the current culture of transition within a PMC SB Clinic. The creation of an evidence-based protocol for best practices for transition to adult care for the YASB, underpinned by the theoretical model of Glass-McAtee (Glass & McAtee, 2006) and guided by the evidence-based practice Model for Evidence-Based Practice Change (Rosswurm & Larrabee, 1999), has the potential to serve as a future foundation of transition care at the PMC. Related research surrounding transition to adult health care, supported through the DNP Essentials, demonstrated a need for a best practices evidence-based approach to facilitate transition to support the long term health of the YASB.

Appraisal Instrument

The Appraisal of Guidelines for Research and Evaluation II Instrument (AGREE II) was applied to the critically appraised evidence and guided the development of a best practices transition protocol (see Appendix E). The AGREE II instrument (see Appendix D) facilitates development and decreases variability in guidelines and protocols through a rigorous and systematic process (Brouwers et al., 2010). The instrument is based on six quality domains including: a) scope/purpose, b) stakeholder involvement, c) rigor of development, d) clarity, e) applicability and f) editorial independence. AGREE II offered a 23 item tool to provide detailed criteria of basic essentials needed to produce a best practices protocol. The tool provided a

structured and rigorous methodology to ensure that final recommendations were applicable and robust when applied to the clinical environment (Brouwers et al., 2010, p. 4).

Chapter Three: Methods

Evidence-based practices bring together provider experience, synthesis of multidisciplinary evidence and patient and family values and preferences to provide best practices in patient care (Melnyk & Fineout-Overholt, 2011). Current institutional prevalence data revealed that approximately 20 percent of patients attending the PMC SB Clinic were over age 21. Therefore the creation of an evidence-based protocol for best practices for transition to adult care for the YASB, underpinned by a theoretical model and guided by evidence based practice, had the potential to propose future directions for improvement of transition care in the PMC SB Clinic.

Research Design

A retrospective data review and focus group was used for this project. An application to the PMC Institutional Review Board (IRB) was made with the ruling of "Study not human subjects' research". The application was made to ensure that proper procedures were followed during the implementation of the focus group. The potential for dissemination of knowledge outside of the project site further substantiated the need for PMC IRB review. Therefore, despite the fact that this project would not involve human subjects, it remained important to ensure that appropriate IRB policies and procedures were followed regarding the protection of patient data. An application was submitted and approved to the PMC Continuing Education Department to obtain 1.0 contact education hours for those that attended the Focus Group and presentation of the evidence-based best practices transition protocol developed during the DNP capstone project.

Focus Group

This DNP capstone project performed a focus group with the providers in the PMC SB Clinic using a semi-structured question based format. The purpose of the focus group was to

gather the SB Clinic providers' attitudes, beliefs and experiences surrounding transition and compare them to evidence-based best practices to determine gaps in transition care. The overall intent of the focus group was to serve as a methodology to study and understand the phenomena of current practices at the PMC SB Clinic.

The DNP student chose a focus group as the research design to provide a mechanism to collect data regarding perspectives and practices surrounding transition to adult health care in the PMC SB Clinic. Formulated questions were provided in a semi-structured interview process. The focus group process held the potential to discover the SB Clinic provider groups' culture, practices and experiences surrounding transition (Doody et al., 2013; Freeman, 2006; McLafferty, 2004). The focus group component of the DNP project explored the process of transition as it currently exists in the PMC providing a method to describe current practices surrounding transition within the PMC SB Clinic (Beyea & Nicoll, 2000; Doody et al., 2013; Then et al., 2014).

Sample

The PMC SB Clinic has a multidisciplinary construct that includes the following disciplines that are involved in transition of patients to adult providers: a) Advance Practice Registered Nursing (APRN), b) medicine, c) social work and d) neuropsychology. Following approval of the project by the PMC IRB, an electronic invitation was sent to 10 providers to attend the focus group session. Of the initial invited group, eight providers attended the session; one physician did not attend secondary to scheduling conflicts and one APRN did not attend secondary to resignation from the PMC SB Clinic.

Methods and Instruments

A one-hour semi-structured focus group was conducted with the providers of the PMC SB Clinic. The session was digitally recorded and transcribed by the DNP student to identify themes brought forth through the structured questions. A focus group methodology was chosen to provide an in depth exploration and accurate representation of providers current practices and beliefs surrounding transition in the PMC SB Clinic (Anderson, 2010).

Structured questions presented to the focus group were as follows:

1. In your work in the SB Clinic, what has been your experience/role with transitioning patients over the age of 21 years?
2. When, in your opinion, should patients with spina bifida be transitioned to adult care?
3. What do you feel is the biggest barrier to successful transition for the young adult with spina bifida to adult care?

Questions were designed to obtain the perceptions of providers in the SB Clinic regarding transition in a permissive, non-threatening environment with the goal of understanding opinions, beliefs and experiences surrounding transition of the YASB to adult health care (Beyea & Nicoll, 2000; Freeman, 2006; Then et al., 2014).

Responses from the providers were not linked to the respondent. Data from the recording was coded and key themes regarding providers' current practices, experiences and beliefs surrounding transition to adult care were compiled and categorized (Beyea & Nicoll, 2000; Doody et al., 2013; Freeman, 2006; McLafferty, 2004; Then et al., 2014). Categorization was divided into three theme areas that were discovered during the systematic literature review conducted for the creation of the best practices protocol (see Appendix E). The three discovered

themes included: a) position statements, b) perspectives of YSHCN and their families and c) foundations of transition programs.

Following the data collection phase of the Focus Group, a Power Point presentation was provided to the group to present the evidence-based best practices transition protocol. The group was provided 1.0 hour Continuing Educational Units for attending the entire focus group event.

Data Analysis

Perspectives and practices that were discovered during the focus group were compared and contrasted against evidence-based transition practices detailed within the protocol. From this comparison, gaps in current practices compared to the evidence were discovered. A Gantt chart was developed to direct future steps that the DNP student will take to develop a formal transition program at the PMC (see Appendix G). A Gantt chart provides a methodology to detail a timeline of tasks and events when developing a project management plan (Gantt, 2012-2016).

Evidence based on expert, provider, patient, family, organization and institutional practices have identified a need for improved transition from pediatric to adult health care for the YASB. A focus group explored current practices of the delivery of transition care in the PMC SB Clinic that were previously unknown. The comparison of current practices against a model directed evidence-based best practices transition protocol identified gaps in current practices when compared to best practices found in the literature. Utilization of these findings in a planned manner directed by Gantt methodology provides the potential to improve the long term health and wellness of adult patients in the PMC SB Clinic.

Chapter Four: Findings

Results

Critical appraisal of the systematic review of literature surrounding transition to adult health care revealed three major themes: a) position statements, b) perspectives and experiences of YSHCN and their families and c) foundations of existing transition programs. Responses of the providers in the focus group regarding current practices in the PMC SB Clinic were compared to the three theme areas to discover gaps in current practices founded on evidence-based recommendations.

Within the PMC SB Clinic, the primary barrier to transition to adult health care for the YASB is the lack of a locally available adult multidisciplinary SB Clinic. Although the PMC is located in an urban metropolitan area, there currently was no adult counterpart clinic that existed to transition patients to for multidisciplinary adult health care. The following is a discussion of findings from the focus group study compared to evidence-based best practices to discover gaps in current transition practices in the PMC SB Clinic.

Synthesis of Focus Group Response Compared to Evidence-Based Position Statements

Focus group findings were compared and contrasted to evidence-based position statement literature to determine gaps in current PMC SB Clinic practices (see Appendix H). Evidence based position statements endorsed the following recommendations: a) begin transition at age 12 years, b) formal transition plan by age 14 years, c) Transition Coordinator responsible for transition care and d) up-to-date portable transition summaries (AAP, 2002; AAP, 2011). The PMC SB Clinic provided pediatric trained case managers that directed the care of the patients that attended the PMC SB Clinic. Patients that attended the PMC SB Clinic were never required

to transition out and were permitted to attend the clinic throughout their entire lives. The PMC SB Clinic had no dedicated employee to manage transition to adult health care for their patients (a Transition Coordinator) or a formal program or plan for transition to adult health care. One focus group respondent articulated a fear of not having an organized model to transfer patients to stating *"Few of our patients transfer out of our clinic; there is nowhere for them to go. Recently we transferred one of our patients out and he died at his local hospital at age 37."* The focus group acknowledged the importance of transition and acknowledged that no formal transition plan was a deficit within their clinic stating, *"Transition should be introduced before middle school."* and *"We have no formal transition plan in place for our patients mostly because we have nowhere to transition them to. There are few adult providers willing to accept our patients because of their complexity."* Providers stated that families verbalize a resistance to leaving the PMC SB Clinic, *"Our families are afraid to leave the SB Clinic."*

Literature recommends that patients should be transitioned to adult health care by age 18 to 21 (AAP, 2011). However, literature also acknowledges that there are variances within the SB population due to deficits in executive functioning (Greenberg, 2001). Focus group responses of opinions and practices were significantly varied in their judgement of when patients should be transferred to adult care. Responses included:

"Because of intellectual and developmental disabilities in the SB population, transition must be developmentally based. You cannot transition patients purely based on their actual age."

- *"Patients should be transitioned to adult care by age 30 years, this is when adult health problems usually start to occur and are best addressed by adult providers."*
- *"Patients and families should not be transferred out of our care until they are ready."*

Expert opinion literature recommended that a cumulative, accessible and portable summary of patients' health care records should be present for patients as they transition to adult health care (AAP, 2011). In rare cases if PMC SB Clinic patients are transitioned, the clinic gathers as much of the patients' health care records as they can, but it is not a common practice to maintain a portable health care summary for patients in the SB Clinic. Responses from the focus group recognized that they have experienced challenges when they have tried to transition patients stating, *"One of the most difficult parts of transition is the transfer of a lifetime of medical records and imaging studies."*

Despite the fact that over 20 percent of the patients in the PMC SB Clinic are over age 21, the providers within the clinic are mostly pediatric board certified and licensed. Focus group respondents acknowledged that they were part of the resistance to transition to adult health care stating, *"We are part of the problem. We don't "let go" of our patients. We don't promote personal responsibility because we do everything for them and do not promote independence for their adult medical needs."* This finding was consistent with the literature that found that pediatric providers demonstrate their own resistance to transitioning patients (Binks et al., 2007; Doug et al., 2011).

Synthesis of Focus Group Responses compared to Evidence Based Perspectives and Experiences of YSHCN and Families

Focus group findings were compared and contrasted to evidence-based patient and family perspectives on transition literature to determine gaps in current PMC SB Clinic practices (see Appendix I). Family priorities for YSCHN included protection of health, safety and security, plans for meaningful education/employment and a concern for a lack of activities for YSHCN's to be involved in after high school. Research literature found that facilitators of transition

included independence, self-decision making/self-advocacy skills and educational and/or employment goals (Berry et al., 2013; Betz et al., 2010; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Reiss et al., 2005; Ridosh, Braun, Roux, Bellin, & Sawin, 2011; Young et al., 2009). The focus group discussed that within the SB Clinic, promotion of self-care skills such as urinary catheterization of dolls is started early in life. However there is no formal educational plan regarding the condition of SB that ensures that patients within the PMC SB Clinic understand SB and its global impact.

The PMC SB Clinic provides a dedicated social worker and neuropsychologist and holds a yearly SB camp for patients over age eight years old. Providers in the focus group stated, "*We assess our patients for intellectual disabilities beginning early in childhood to qualify them for services and supports." "We ensure individual educational plans and transition plans after high school are in place for our patients within their school if they are developmentally able to have them in place. We make sure that they are hooked up with their local board of developmental disabilities."* However, the current clinic construct did not support the life course model of a program which includes a dedicated plan for discussing education, employment, living and social activities throughout the lifespan. The focus group did not acknowledge this deficit within their clinic.

Literature found that four major factors for successful transition include: a) a developmentally based life course model, b) a maintained portable medical summary, c) a financial plan for support of needs and d) pediatric and adult providers working together during transition (Van Staa et al., 2011). Barriers that YSHCN/family literature acknowledged that impact successful transition included: a) intellectual disability, b) immobility challenges, c) lack of a multidisciplinary adult health care model and d) lack of funding/insurance to help with

health care needs (Berry et al., 2013; Betz et al., 2010; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Reiss et al., 2005; Ridosh, Braun, Roux, Bellin, & Sawin, 2011; Young et al., 2009). The focus group articulated some of these concerns stating, *"Major barriers for our adult patients are financial, insurance, mobility and transportation challenges."* The focus group went a step further by discussing that their adult patients did not plan for health care emergencies stating, *"Our young adult patients do not understand the importance of having adult health care access. They wait until something really bad happens to them and then they call us."* As stated previously several major factors found during the focus group included difficulty in finding adult providers to accept the YASB, no local multidisciplinary adult SB Clinic and lack of a maintained portable health care summary. The PMC SB Clinic does not provide a formal life course based model of care within the clinic.

Synthesis of Focus Group Responses Compared to Foundations of Programs

Focus group findings were compared and contrasted to evidence-based foundations of current SB transition programs literature to determine gaps in current PMC SB Clinic practices (see Appendix J). Literature endorsed that foundations of transition programs should include: a) transition is started early, expected and built on a life course model, b) ensure education, employment and activity goals, c) involve the young adult in transition planning, d) provide knowledge of SB and self-care and e) need for a multidisciplinary adult model clinic (Binks et al., 2007; Crowley, Wolfe, Lock, & McKee, 2011; Doug et al., 2011; Liptak, Kennedy, & Dosa, 2010; Lugasi, Achille, & Stevenson, 2011; Rearick, 2007; Stewart et al., 2010; Van Staa et al., 2011). The PMC was a free standing children's hospital with no direct physical link to an adult medical campus, had pediatric case managers and did not have a formal Transition Coordinator paid position. When comparing the literature of transition programs to the PMC SB Clinic, as

previously stated, there was no local multidisciplinary adult SB clinic and a lack of collaboration between pediatric and adult providers. Respondents of the focus group acknowledged concerns with these limitations stating, *"If patients are transferred out to a non-multidisciplinary model they have huge limitations because of transportation and mobility because it is almost impossible for them to attend appointments at so many subspecialists"*.

Literature regarding exemplar transition programs for YSHCN's discussed that they are financially maintained through health care system support, grants and philanthropic funding (Berens & Peacock, 2015; Betz, Smith, VanSpeybroeck, Hernandez, & Jacobs, 2015; Forcier et al., 2011; Kaufmann-Rauen, Sawin, Bartelt, Waring, & O'Connor, 2013; Sawin et al., 2014). During the focus group, this was acknowledged as a concern, *"Our clinic receives financial backing from pediatric based funding sources that are not available in the adult world of health care. How will the adult health care system fund such a labor intensive clinic?"*

Discussion

The PMC SB Clinic provided care to patients with SB and their families that began at birth and continued throughout their entire lives. The primary reason for this was because there was no multidisciplinary adult SB clinic to transfer them to as they transitioned into adulthood. Patients with SB require multiple specialty health care providers to address the systemic impact of their condition. If patients are transferred to multiple adult subspecialists it would be challenging to attend all of the appointments. Attending multiple different appointments is impacted by factors such as transportation, mobility challenges and the sheer impact of scheduling up to a dozen different sub-specialty appointments. If the PMC SB Clinic did not provide adult care to patients with SB the evidence has demonstrated that in many cases patients

would not follow-up on their health issues which results in worsening of health and co-morbid conditions (Callahan & Cooper, 2006).

However, evidence clearly demonstrated that adult patients with SB need and deserve health care that is designed for their needs as they mature. The purpose of this project was to explore current perspectives and practices within the PMC SB clinic and contrast them with evidence that described best practices for transition to adult health care for patients with SB. This project was not done to judge the current PMC SB Clinic construct; rather it was done to propose potential ways to help improve transition care at the PMC SB Clinic.

The first and foremost recommendation is for the PMC to reach out to local adult providers in the metropolitan area to begin discussions regarding the development of a multidisciplinary clinic to meet the needs of adult patients with SB. Literature discussed one model in which an adult spinal cord injury clinic was the receiving clinic for patients transitioned out of a pediatric SB clinic (Sawin et al., 2014); a construct which is available in the PMC metropolitan area. However, this would have to be tempered with the fact that the PMC supports programs that provide clinic care to adults with complex health care needs within their pediatric facility (Nationwide Children's Hospital [NCH], 2012).

Comparison of focus group responses/current PMC SB practices with evidence-based best practices revealed the following global recommendations to improve the current PMC SB Clinic construct (see Appendix F):

- A formal and routinely updated life course model based transition plan made with the involvement of the YASB
- A life course model clinic construct addressing education, employment, living, social and community integration

- A Transition Coordinator position dedicated to the coordination of transition to adult health care for YASB using the life course model construct
- Utilization of the electronic health record to maintain a cumulative portable health care summary
- Partnering with adult providers in the community to facilitate acceptance of adult patients with SB
- Introduction of adaptive sports involvement opportunities
- Mentoring programs with YASB and their parents to allow sharing of life skills learned for those that have transitioned into adulthood.

DNP Student Plan Following Capstone Project

Recommendations that could be made to the current SB Clinic construct include (see Appendix F): a) recommend to PMC leadership the introduction of a Transition Coordinator position, b) introduction of adaptive sports and mentoring programs for YASB and their families, c) providing education to local adult primary care providers regarding SB to establish referral providers for adult primary health care for YASB, and d) creation of ongoing health care summaries using the electronic health record.

Proposed next steps for the DNP student to improve overall transition care in the PMC SB Clinic include (see Appendix G):

- Meet with the PMC SB Clinic Leadership and provide a PPT presentation regarding evidence based best-practices for transition to adult health care contrasted with focus group findings of current practices in the PMC SB Clinic
- Formulate a plan with the SB Clinic leadership and providers regarding proposed future directions for adult SB care including the use of existing spinal cord injury adult clinics,

establishment of a new adult based SB Clinic at an adult facility or establishment of an adult PMC SB Clinic with adult based providers

- Meet with PMC leadership to propose decided upon future direction proposal for adult SB care.

Conclusions

The focus group with providers from the PMC SB Clinic was conducted to explore current perspectives and practices for transition to adult health care for the young adult with spina bifida (YASB). Responses from the focus group were organized into themes that were compared against an evidence-based best practices transition protocol. This protocol was developed from a systematic critical review of evidence regarding best practices for transition to adult health care for youth with special health care needs (YSHCN). This effort was performed to determine gaps in current practices compared to critically appraised best practices. A baseline understanding of current practices was necessary before any quality improvement effort is undertaken to improve transition care in the PMC SB Clinic. Evidence-based best practices discovered during the systematic review have the potential to serve as a benchmark for future development of a formal transition program in the PMC SB Clinic.

Chapter Five: Summary, Limitations and Implications

Study Summary

Transition to adult health care represents a significant event in the developmental process of the YASB that has lifelong implications. This DNP capstone project sought to explore the phenomena of transition in a PMC SB Clinic and contrast it with evidence-based best practices to identify gaps in the current PMC SB Clinic construct. Current provision of adult care for those with SB in the PMC SB pediatric based model, when compared to current evidence-based best practices, clearly demonstrate that change is needed. Although the overall intent of the current clinic construct "makes do" with current resources, evidence found in the literature provides recommendations that have the potential to improve the quality of care provided to the YASB that can result in a lifelong positive impact.

Limitations

This project was done by a DNP student that was a direct pediatric APRN provider within the PMC SB Clinic. Because of the students' direct involvement, her analysis of the PMC SB Clinic could serve as both a benefit as well as a limiting factor in the provision of an objective viewpoint. If the focus group was directed by an outside source with training in principles such as Lean Six Sigma, other factors could have been discovered through the focus group. Additionally, this was a DNP student project and not a formal qualitative study. In the future, the DNP APRN could partner with a PhD counterpart to perform a formal qualitative study of PMC SB Clinic perspectives and practices as well as the perspectives and practices of the PMC regarding transition to adult health care strategic plans and goals.

Financial considerations regarding the development of such a significant and considerable program were not addressed within this project. Issues such as lost income to the

PMC if adult patients are transitioned out of the PMC have the potential to result in not only financial but strategic plan losses to the PMC. The financial impact of the development of an adult multidisciplinary SB Clinic was also no projected. Once decisions are made regarding the direction of the PMC for adult SB care, a formal financial impact study will be necessary to ascertain the cost surrounding the introduction of changes to the current PMC SB program.

Literature demonstrated that funding of successful adult SB programs relied on financial support from medical centers, grants and philanthropic sources. This presents a significant consideration when developing an adult based SB Clinic due to the lost support that is available in a pediatric construct though funding sources such as the Bureau for Medically Handicapped Children. With the advent of value based versus volume based health care, perhaps the Patient Protection and Affordable Care Act could provide funding to a multidisciplinary value based adult SB Clinic (Patient Protection and Affordable Care Act, 2010).

Implications for Nursing Practice and DNP Essentials

This DNP Capstone project represents a compilation of three years of training in the principles set forth by the American Association of Colleges of Nursing, Essentials of Doctoral Education for Advanced Nursing Practice (AACN, 2006) applied to the concept of transition to adult health care for youth with special health care needs. The concept of transition impacts not only those with SB but permeates throughout pediatric health care as lives continue to be extended through advances in health care. Through the rigor of training that the "Essentials" demand, the DNP APRN is well prepared to undertake significant clinical problem analyses such as these with the intent to improve health care.

The DNP Essentials were a guiding force throughout this DNP Capstone Project. Essential I: Scientific Underpinnings for Practice and Essential III: Clinical Scholarship and

Analytical Methods for Evidence-Based practice inspired the use of the Model for Evidence Based Practice Change (Rosswurm & Larrabee, 1999) and the Glass McAtee Model (Glass & McAtee, 2006) to guide the development of the best practices evidence-based protocol for transition to adult health care. A focus group was conducted to compare current practice to evidence-based best practices in transition care. A protocol was developed through rigorous principles of scholarship and analytical methods.

The very basis of this project embodies Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking. The DNP student assumed a leadership role through analyzing evidence based best practices and applied them to a clinical system. This was with the end goal of the application of lessons learned to improve a system of care.

Through the proposal of the development of a portable electronic health record, DNP Essential IV: Information Systems/Technology and Patient Care Technology for the Improvement and Transformation of Health Care was included in the project. With the advent of the Patient Protection and Affordable Care Act, this DNP Capstone Project represents an attempt to design a value based multidisciplinary quality improvement project to improve health outcomes for a vulnerable underserved population. Therefore, this project has the potential to influence Essential V: Health Care Policy for Advocacy in Health Care, Essential VI: Interprofessional Collaboration for Improving Patient and Population Health Outcomes and Essential VII: Clinical Prevention and Population Health for Improving the Nations' Health.

The DNP Essentials have provided the DNP student with the knowledge and skills necessary to provide the highest level of care possible in advanced nursing practice; Essential VIII. It is the hope of this student that the aptitudes learned in The Ohio State University DNP

program will continue to improve the care that she delivers every single day to the patients and families that she serves.

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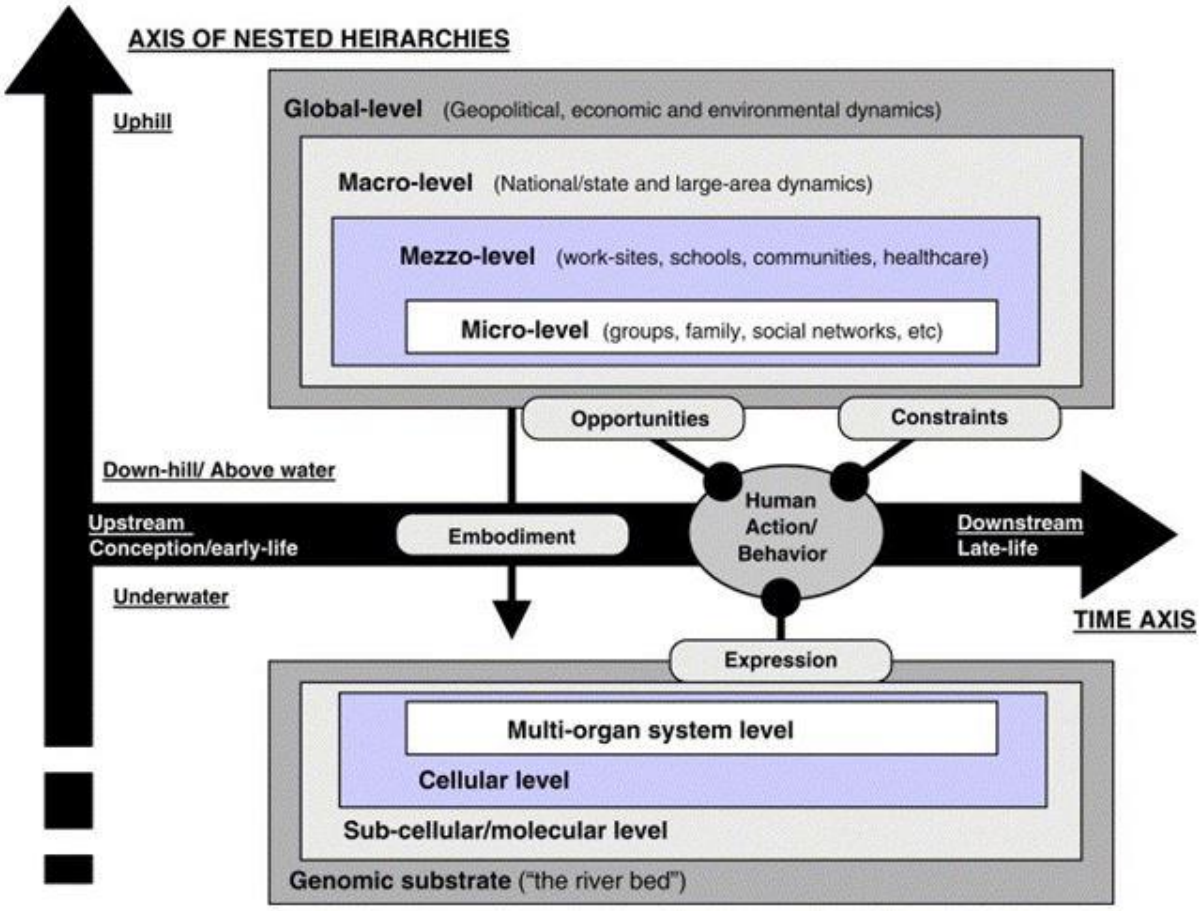
Appendix A
Glass McAtee Model



(Glass & McAtee, 2006)

Appendix B								
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)								
Database (Plus limits)	**Search Terms**	**Records Identified**	**Records After Duplicates Removed**	**Records Screened**	**Records Excluded**	**Full Text Kept**	**Full Text Excluded / Reserve Collection**	**Final number of articles kept**
PubMed (last 10 years)	YASB + TTAC							
	YASB + TTAC + MCC							
	YASB + TTAC + MCN							
	YASB + TTAC + PS							
	YASB + TTAC + FS							
PubMed (no time limit)	YASB + TTAC							
PubMed (systematic review)	YASB + TTAC							
Cochrane Library	YASB + TTAC							
	YSHCN + TTAC							
	TTAC							
CINAHL (last 10 years)	YASB + TTAC							
	YASB + TTAC + MCC							
	YASB + TTAC + MCN							
	YASB + TTAC + PS							
	YASB + TTAC + synthesis							
	YASB + TTAC + Evidence based practice							
National Guideline	YASB + TTAC							
	YASB							

Appendix B								
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)								
Database (Plus limits)	**Search Terms**	**Records Identified**	**Records After Duplicates Removed**	**Records Screened**	**Records Excluded**	**Full Text Kept**	**Full Text Excluded / Reserve Collection**	**Final number of articles kept**
Clearing House	TTAC							
	SB + TTAC							
	Transition + Adult care + YSHCN							
Web of Science (last 10 years)	YASB + TTAC							
Health Source: Nursing/ Academic Edition	YASB + TTAC							
Ovid MEDLINE (last 10 years)	YASB + TTAC							
	YASB + transition							
	spina bifida + TTAC							

Legend: FS=Family satisfaction; MCN=Management of changing needs; MCC=Management of chronic conditions; PS=Patient satisfaction; SB=Spina bifida; TTAC=Transition to adult care; YASB=Young adult with spina bifida; YSHCN=Youth with special health care needs; * Protocol only.

Appendix C
Model for Evidence Based Practice Change
Integrating the Evidence into a Transition Protocol

MEBPC Step	Methods and Measures
Step 1: Assess the need for change	• Guided by Glass McAtee Model, PICO question, and Roy Adaptation Model • Obtain institutional prevalence data of number of patients that attend the SB clinic that are over the age of 21 years
Step 2: Locate the best evidence	• Search terms: (a) young adult with spina bifida, (b) transition to adult care, (c) management of changing needs, (d) management of chronic conditions, (e) patient satisfaction, (f) family satisfaction, (g) spina bifida, (h) youth with special health care needs, (i) transition and, (j) adult care. • Databases queried: (a) PubMed, (b) Cochrane Library, (c) CINAHL, (d) National Guideline Clearing House, (e) Web of Science, (f) Health Source: Nursing/Academic Edition, and (g) Ovid MEDLINE. • Data resources: Google Chrome search engine and The Ohio State University Health Sciences Library System • Meaningful limits: Within all databases, with the exception of the National Guideline Clearing House, past 10 years will be placed on the search. In the PubMed database, systematic reviews will be queried. In the CINAHL database, these limitations will be queried: (a) research article, (b) synthesis, and (c) evidence-based practice.
Step 3: Critically analyze the evidence	• Evidence included based on the preferred reporting items for systematic reviews and meta-analyses (PRISMA) method (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009). • Included evidence critically evaluated by the Melynk and Fineout-Overholt (2011) Rapid Critical Appraisal Tools and Evaluation and Synthesis Tables.
Step 4: Design practice change	• Appraisal of Guidelines for Research and Evaluation II Instrument (AGREE II) to the critically appraised evidence to guide the development of the transition protocol (Brouwers et al., 2010).
Step 5: Implement and evaluate change	Implementation, Evaluation, Integration and Maintenance of transition protocol to occur following completion, evaluation, revision and acceptance by the PMC and the SB clinic provider team.
Step 6: Integrate and maintain change	

(Rosswurm, & Larrabee, 1999)

Appendix D
AGREE II
(**A**ppraisal of **G**uidelines, **Re**search and **E**valuation)

AGREE Domain	Item
Domain 1: Scope and purpose	1. Overall objectives specifically described. 2. Health questions covered are described. 3. Population to whom the guideline is meant to apply specifically described.
Domain 2: Stakeholder involvement	4. Guideline development group includes individuals from all relevant professional groups. 5. Views and preferences of target population have been sought. 6. Target users of the guideline have been defined.
Domain 3: Rigor of development	7. Systematic methods used to search for evidence. 8. Criteria for selecting evidence clearly described. 9. Strengths and limitations of body of evidence clearly described. 10. Methods for formulating recommendations clearly described. 11. Health benefits, side effects and risks have been considered in formulating recommendations. 12. Explicit link between recommendations and supporting evidence. 13. Guideline externally reviewed by experts prior to publication. 14. Procedure for updating guideline provided.
Domain 4: Clarity of presentation	15. Recommendations specific and unambiguous. 16. Different options for management of condition or health issue clearly presented. 17. Key recommendations easily identifiable.
Domain 5: Applicability	18. Guideline describes facilitators of and barriers to its application. 19. Guideline provides advice or tools on how recommendations can be put into practice. 20. Potential resource implications of applying the recommendations have been considered. 21. Guideline presents monitoring or auditing criteria.
Domain 6: Editorial independence	22. Views of the funding body have not influenced the content of the guideline. 23. Competing interests of members of the guideline development have been recorded and addressed.

(Brouwers et al., 2010)

Appendix E
Evidence-Based Best Practices Transition Protocol

Position Statements, Perspectives, Foundations and Exemplar Programs - Summaries

Position Statements - Summary

References	Best Practices
AAP, 2002; AAP, 2011	• Begin transition by 12 years • Written plan by 14 years • Transfer of care between ages of 18 and 21 with assurance of chronic condition management for YSHCN • Dedicated transition coordinator • Up to date, portable, accessible transition summary • Plan with family and YSHCN, review/update plan, address chronic disease management

YSHCN/Family Transition Perspectives and Experiences – Summary

References	YSHCN/Family Perspectives on Transition
Berry, 2013; Betz, 2010; Rehm, 2012; Reiss, 2005; Ridosh, 2011; Young, 2009	YSHCN perspectives: • Facilitators of transition: encourage/promote independence, self-management, decision-making and self-advocacy • Desire medical/social independence • Pediatric providers talk to my family and not to me • Impaired functional status (immobility) major barrier to independence • Adulthood = independence, educational/employment goals Parent/Family perspectives: • Cognitive abilities major barrier to independence • Concerned about lack of adult multidisciplinary models of care • Concerned about child's ability to obtain insurance coverage • Priorities for children: health protection, safety, security, meaningful educational/employment/activity programs after high school

References	YSHCN/Family Perspectives on Transition
	General: • Four major transition factors: a) is a developmental process (begin early in childhood), b) medical/social summary at transition; c) financing of health care needs; d) pediatric/adult providers must partner together • Planned transfer of care and care-coordination important • Early parental promotion of independence resulted in good outcomes. If parent not confident with child resulted in low levels of self-care. • Cognitive impairment is a critical factor (i.e. need for neuropsychiatric testing) • Camps, adaptive sports and peer relationships are facilitators of independence • Provide targeted interventions: a) promote social/peer relationships, b) job skills, c) self-management, d) YSHCN involvement in care decisions • Shy YSHCN's less likely to take responsibility

Foundations of Transition Programs - Summary

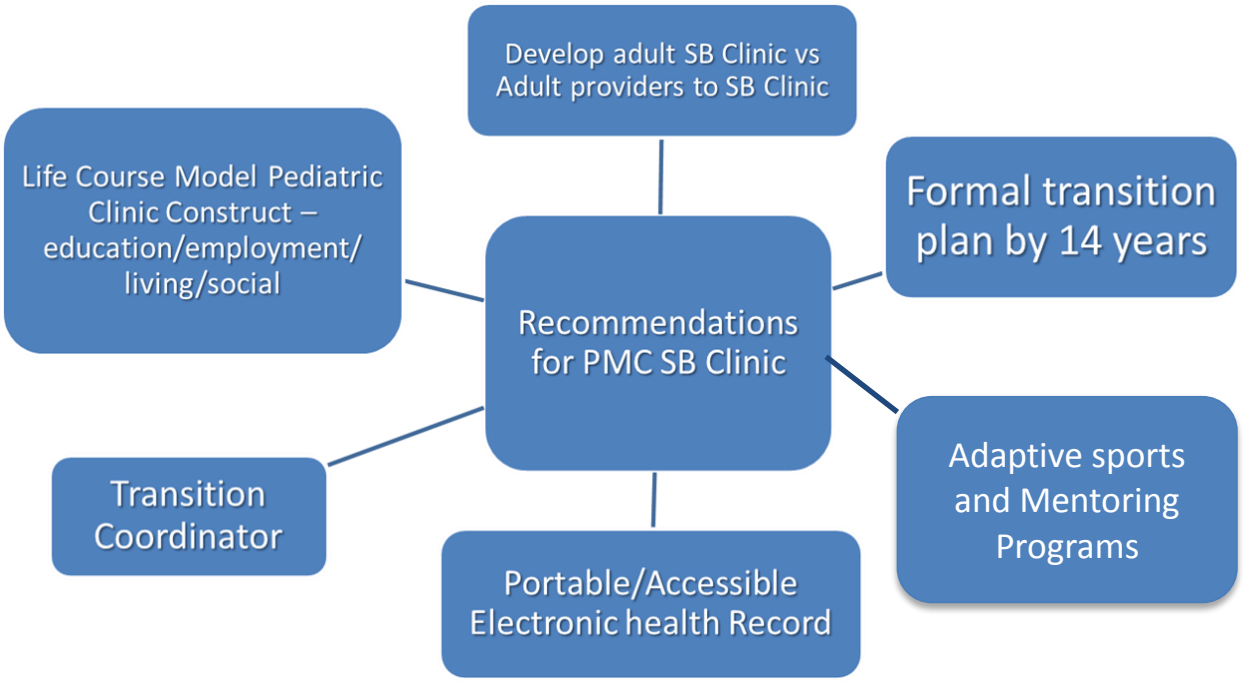
References	Transition Programs - Best Practices
Binks, 2007; Crowley, 2010; Doug, 2011; Liptak, 2010; Lugasi, 2011; Rearick, 2007; Stewart, 2010; van Staa, 2011	• Five conditions for successful transition: a) planned/expected event, b) expectations of YSHCN addressed, c) begin early/promote independence, d) formal plan, e) ensure environment that supports transition (education/empowerment) • Supportive factors: knowledge of condition/self-management, self-awareness, self-determination, self-advocacy, effective coping, resilience, mentor programs • Holistic, life-course model perspective. Domains: education, employment, living, social, community • Formal transition plan with YSHCN and family involvement • Transition coordinator, support before/during/after transition • Coordinated approach between pediatric and adult provider. Planned process before transition. Visit to adult provider before full transition.

References	Transition Programs - Best Practices
	• Comprehensive medical summary, health care passport • Interested/engaged adult provider identified • Internet transition resources

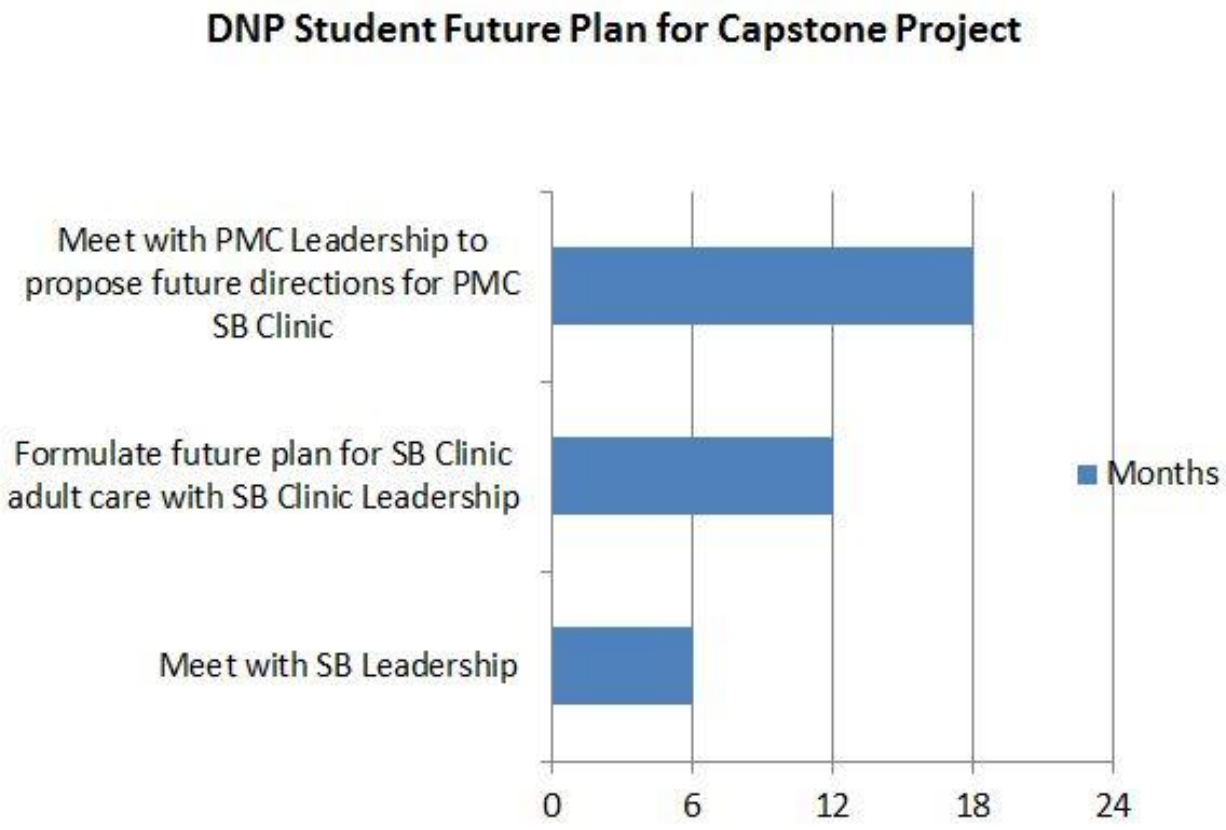
Exemplar Transition Programs – Summary

References	Best Practices
Berens, 2015; Betz, 2015; Forcier, 2011; Lugasi, 2011; Rearick, 2007; Stewart, 2010; van Staa, 2011; Young, 2009	Free standing adult clinics for YSHCN's (3 articles) • Patients with spina bifida transitioned to an adult Spinal Cord Injury Clinic (2 articles) • Free standing clinic for YSHCN's (1 article) – Funding: grants, philanthropy, medical center support Transition Program within a Pediatric Spina Bifida Clinic – (patients transitioned to an adult clinic after age 21) • Comprehensive nurse led program that includes: weekly monitoring, formal transition plan, self-management training, post-secondary education/volunteer/job training/developmental disabilities services facilitation. • Protocol driven, based on life course model conceptual framework Hospital Based Transition Team • Provide hospital wide transition consultation services using a transition screening tool/checklist for all YSHCN's Life-Course Model for Spina Bifida • Developmentally organized resource that guides preparation for adulthood for the patient with spina bifida Got Transition.org • Federally supported web based resource dedicated to improving transition from pediatric to adult health care for YSHCN's

Appendix F
Current Recommendations for PMC SB Clinic

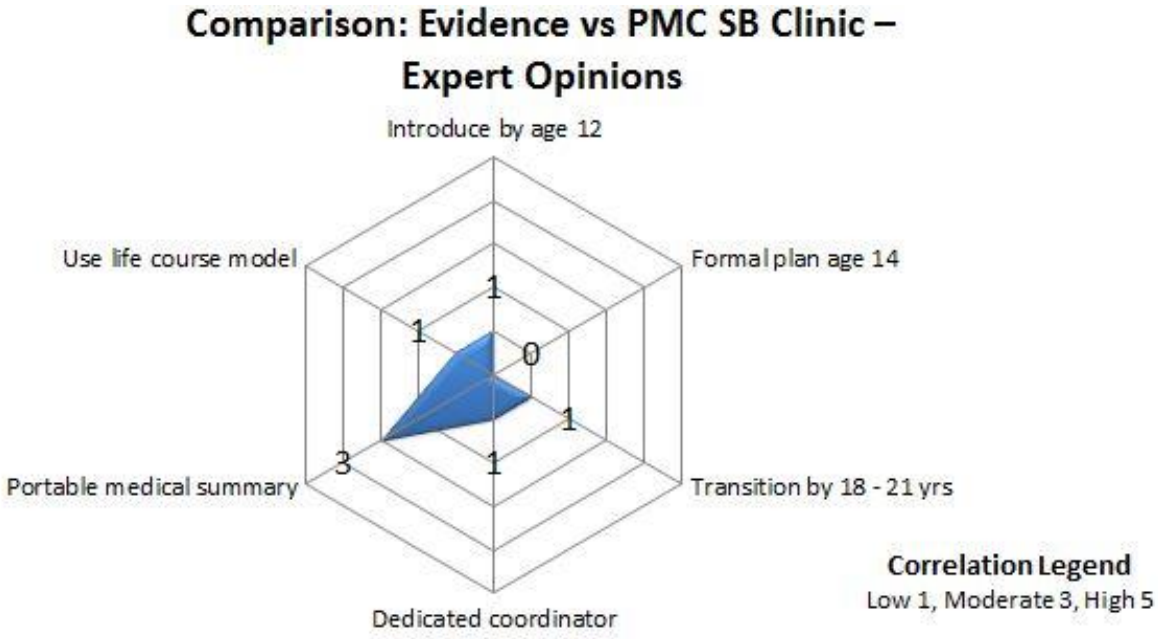


Appendix G
Future DNP Capstone Project Goals



Appendix H

Focus Group Data vs Expert Opinion Literature
Gaps in Current Practices

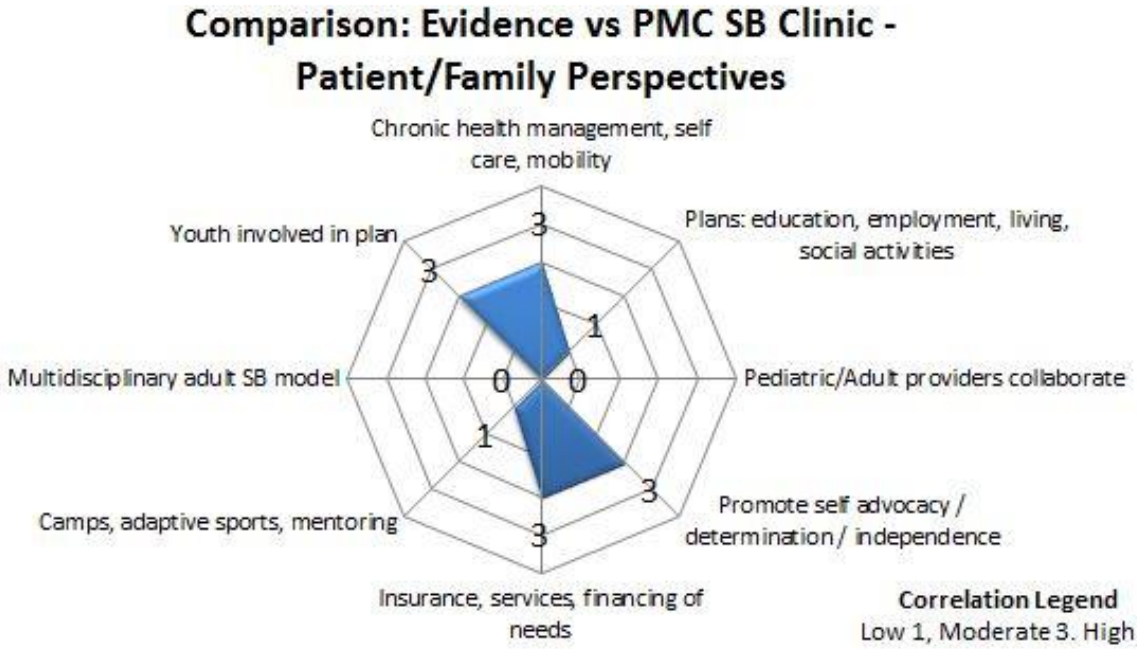


Major Gaps in Evidence Based Best Practices:

- No formal introduction, plan for transition
- Patients/Families receive lifetime care in a pediatric model
- No dedicated Transition Coordinator
- No formal program for education, employment, living, social, community

Appendix I

Focus Group Data vs Patient/Family Perspectives Literature
Gaps in Current Practices

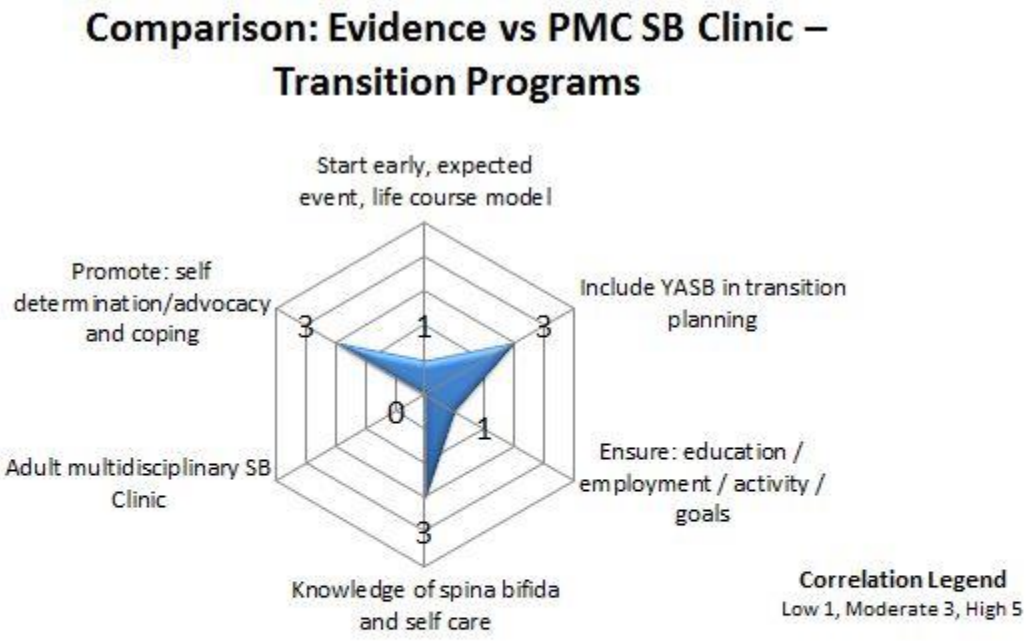


Major Gaps in Evidence Based Best Practices

- No local multidisciplinary adult SB Clinic
- Few adult providers accept SB patients/collaborate with pediatric providers
- No adaptive sports involvement, mentoring program
- No formal program for education, employment, living, social, community

Appendix J

Focus Group Data vs Transition Programs Literature Gaps in Current Practice



Major Gaps in Evidence Based Best Practices

- No local multidisciplinary adult SB Clinic
- No formal transition plan
- Adult care provided in a pediatric model
- No formal program for education, employment, living, social, community